

# A Photo Elicitation Study on Chronically Ill Adolescents' Identity Constructions During Transition

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## Abstract

Adolescence is an important phase of life with increasing independence and identity development, and a vulnerable period of life for chronically ill adolescents with a high occurrence of insufficient treatment adherence. We conducted four photo elicitation focus group interviews with 14 adolescents (12–20 years) with juvenile idiopathic arthritis to investigate identity constructions during transition. Using a discourse analysis approach, six identity types were identified distributed on normal and marginal identities, which were lived either at home (home arena) or outside home with peers (out arena). Most participants positioned themselves as normal in the out arena and as ill in the home arena. Few participants positioned themselves as ill in an out arena, and they described how peers perceived this as a marginal and skewed behavior. This study contributes to a better understanding of why it can be extremely difficult to live with a chronic illness during adolescence.

## Keywords

photovoice, focus groups, discourse analysis, illness and disease, chronic, transition, identity, adolescence

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I felt that the arthritis took over my identity, and that I was just this ill person who could not do anything normal [but] I've tried to turn it into something positive in order not to crack up.

—Petra.

Adolescence is a complex physical, cognitive, social, and emotional transition. When this transition is confronted with physical disease and its treatment (including the side effects), the individuals' resilience and ways of adaptation may influence their construction of identity. These processes may be best explored in diseases that affect patients in childhood and continues into adulthood. Juvenile idiopathic arthritis (JIA) is the prime example of this scenario. JIA is one of the most common chronic diseases with onset in childhood, it has a female predominance (Gowdie & Tse, 2012), and it may be burdensome due to pain and restricted physical capabilities though not easily identified by the patients' outer appearance. Symptoms fluctuate, and the outcome and prognosis are variable, however; about 50% persist to have symptoms in adulthood (Gowdie & Tse, 2012). JIA may cause severe pain, growth disorders, malnutrition, and decreased health-related quality of life (McKeever & Kelly, 2015). A review regarding barriers to

medication adherence among chronically ill adolescents (JIA included) concluded that health professionals should pay special attention to adolescents' sense of normality as a part of their construction of identity (Hanghøj & Boisen, 2014).

This study grew out of an interest in how best to support chronically ill adolescents' identity development during transition because there is very sparse knowledge about different identities and how they change. Knowledge about what kinds of identities chronically ill adolescents develop and associate with, as well as how identities change between places and in interactions with other people, is necessary when working with adolescents during transition, because identity is a key aspect of defining "Who am I, and what will I do in life?" Thus, our research question was: Which identities do chronically ill adolescents construct during transition?

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## Chronically Ill Adolescents and Identity

Identity is the traits of a person that characterize or define him or her from others. There are several theoretical approaches to the understanding of identity, among which social constructionism is the one we lean on in this study. According to social constructionism, we are included in various discursive contexts in which we behave differently. We position ourselves differently (play different roles) depending on whom we are together with, and our identities evolve and change throughout life (Jørgensen & Phillips, 2002). Construction of identity can be affected by our body image and the social relationships we interact within. At the time of adolescence, the body is changing rapidly and adolescents have to adapt to new challenges in school and find a role among peers and within society. Furthermore, chronic illness has been described as a biographical disruption, influencing a person's identity and self-image (Nettleton, 2013). Discourse analysis is ideal for the analysis of identities, because discourse is "a particular way of talking about and understanding the world" (Jørgensen & Phillips, 2002). Discourse is rooted in the language by which we express views, beliefs, and the way we live our lives. Discourses add meaning to our life and define us as individuals.

## The Concept of Transition

A way to understand adolescence and disease in relation to identity is by putting it in the perspective of transition theory. Moreover, transition is characterized as a period of disorientation, distress, irritability, anxiety, and depression (Chick & Meleis, 1986). Meleis and colleagues have developed a theory called the midrange transition theory, which illuminates chronically ill adolescents' identity challenges. The theory includes a number of characteristics to define a transition period, for example, change in identity, roles, relationships, abilities, and pattern of behavior (Meleis, Sawyer, Im, Hilfinger, & Schumacher, 2000). According to the midrange transition theory, adolescence is defined as a developmental transition, JIA is defined as an illness transition, whereas two parallel transitions are defined as "multiple transition." Transitions with no identifiable endpoint and a variable course with exacerbations like JIA lead to greater distress and vulnerability than transitions with an identifiable endpoint. When chronically ill adolescents start the transfer process to move from pediatric to adult care, they even undergo a third transition. This is what Meleis et al. (2000) call an organizational transition. Most of the research conducted about chronically ill adolescents and transition has focused on organizational transition.

## Previous Research

Chronically ill adolescents' experience of organizational transition in the context of health care has been well

investigated during the last two decades. Among other things, transition has been investigated in relation to readiness for transfer (Stinson et al., 2014), and in relation to adherence (Javalkar, Fenton, Cohen, & Ferris, 2014; Lawson et al., 2014). Also, a lack of knowledge about own diagnosis and treatment among adolescents because of lack of planned transition have been investigated (McDonagh, 2005; Moons et al., 2001), as well as poor disease control in adolescence because of inadequate transition (Holmes-Walker, Llewellyn, & Farrell, 2007). In addition, transition in a specific rheumatology perspective has been investigated (McDonagh & Shaw, 2012).

Identity in chronically ill adolescents during transition is sparsely investigated (Luyckx, Goossens, Van Damme, & Moons, 2011). Chronically ill adolescents' perceptions of identity changes during a transition process have been assessed in a study of diabetic and renal transplant adolescents. The results suggest that adolescents with a chronic illness perceive themselves as being similar to healthy adolescents with respect to interpersonal identity development (Lugasi et al., 2013). These findings are in line with a study on self-positioning in adolescents with JIA; however, this study concluded that the findings may be seen in a broader perspective of knowledge on JIA patients' social, behavioral, and psychosocial impairment (Fuchs et al., 2013). A study on adolescents with advanced chronic kidney disease (CKD) points out five important themes on identity: inferiority, insecurity, injustice, resilience, and adjustment mentality (Tong et al., 2013).

## Method

We conducted four photo elicitation focus group interviews with 14 adolescents aged 12 to 20 years, who were all following a transition program in a specialized pediatric rheumatology clinic.

## Recruitment and Participants

A purposive sampling technique was used to include participants to the focus groups. Participants were recruited from a randomized controlled transition study placed at Department of Pediatric Rheumatology at the Copenhagen University Hospital Rigshospitalet in Denmark. The inclusion criteria were adolescents 12 to 20 years old with a definite diagnosis of JIA (oligoarticular, polyarticular, enthesitis-related or psoriatic), who were treated with disease-modifying medication, for example, methotrexate or biological agents. All participants of the main transition study were asked to participate in the present focus group study by a personal written invitation. They were contacted by phone by the first author (Signe Hanghøj) 1 week after receiving the letter. The inclusion continued until participants represented all age groups to cover the voice of both younger and older adolescents in a transition process. A total of 14 adolescents were recruited,

11 girls and three boys (mean age 15.9 years). They were divided into four focus groups. Data saturation was reached after three focus group interviews, but as the last focus group interview was already planned, this was still conducted even though it did not add new knowledge to the field. The focus groups varied by the participants' age, socioeconomic backgrounds, educational level (elementary school vs. high school), and physical limitations due to the disease.

### Data Collection

We used photographs to gain insight into adolescents' conceptions and experiences of living with JIA. The method is well described within anthropology, sociology, and ethnography. Clark-Ibáñez describes several ways to apply the method, but the key point is that the pictures—whether they are taken by the participants themselves, found on the Internet, or taken by a professional photographer—are used as stimulus material in subsequent interviews. Photo elicitation is recommended for adolescents because photographs engage them and thus become a suitable communication channel between the researcher and the adolescent (Clark-Ibáñez, 2004).

In this study, participants were asked to take photos themselves based on eight questions, which were sent to them a month before the focus group interview took place. At least one “photo answer” should be sent as reply to each of the following questions: (a) What is the most important thing in your life? (b) What do you think is special about being young? (c) What is particularly important to talk to your doctor about in hospital? (d) What does your illness look like? (e) How do you experience your body? (f) What do you do to be healthy? (g) What do you do when you are unhealthy? (h) What occupies your thoughts?

The participants could opt whether to take photos with their cell phone, a disposable camera (which were provided), or their own camera. Participants were asked to send their photos to Signe Hanghøj a few days before the focus group interview took place, so the photos could be magnified and printed. When the participants showed up to the focus group interview, they were handed their own photos. During the focus group interview, the interviewer (Signe Hanghøj) repeated the questions they had received previously but with new and exploratory questions, for example, “What do you think is special about being young?” followed by a new in depth question, for example, “Is it different being young with JIA than young without a disease?” The interviewer asked one question at a time and the participants answered the questions in turn by explaining their own photos. The participants were asked to describe the deeper meaning of their photos and what associations the photos gave them. All participants showed and explained at least one photo for each of the eight preliminary questions. The purpose of using photos was to start a conversation between the participants. They could also associate freely without the use of photos.

The focus group interviews took place between May 2014 and October 2014 at the Copenhagen University Hospital Rigshospitalet (except one, which took place outside hospital due to logistical reasons). Each focus group lasted between 90 and 120 minutes. They were transcribed verbatim in Danish, and the quotes were subsequently translated into English.

### Ethics

Permission to conduct the study was granted by the Danish Data Protection Agency (No. 30-1197). Formal approval by the local ethical committee was not required according to national and local directives in Denmark. The participants were given a summary description of the project before the focus group interview, informing them that they were guaranteed anonymity. Written informed consent was obtained for all participants. The interviewer (Signe Hanghøj) informed them that data would be published anonymously in scientific journals, and all participants consented.

### Data Analysis of Text

In this study, we adopted a theoretical framework rooted in critical discourse analysis, positioning theory, discursive psychology, and micro sociology (Davies & Harré, 1990; Fairclough, 1992; Goffman, 1963; Staunæs, 2004). This approach integrates different but overlapping traditions, and according to Jørgensen and Phillips (2002), this is fruitful because different perspectives provide various forms of insight into an area and lead to a broader understanding. These different but complementary theories explore identity from either a linguistic, rhetorical, or social perspective, which also bring new perspectives to the concept of transition. *Critical discourse analysis* by Fairclough combines a concrete, linguistic, textual analysis of language with a sociological approach to the analysis of social practices (Fairclough, 1992; Jørgensen & Phillips, 2002). According to Fairclough, discourses contribute to the construction of social identities and subject positions. Using a textual approach, it is possible to analyze power relations in the focus groups by looking at determinants of who should speak and who sets the agenda and the topics to be discussed. The analysis of linguistic concepts contributes to a determination of dominant discourses, which the focus group participants may or may not relate to. *Positioning theory* was developed by Davies and Harré to understand people's identities and social life (Davies & Harré, 1990). Positioning theory focus on how identities are constructed and concretely unfold. Positions are unlike roles, something that is constantly produced and continuously negotiated in social life. Positioning theory suggests that people are positioned in different ways in the conversations they lead, and we can only understand why social episodes play out as they do if we understand the positions that structure them. Positionings can be self-selected as people can mobilize certain discourses in an attempt to put oneself in a special position, or positioning

others can externally impose them. People typically switch between different views of themselves and the discourse changes when switching between different positions. Thus, different positions enable different identities. *Discursive psychology* focuses on the construction of identities, how identities arise, and how they are negotiated and transformed between people (Jørgensen & Phillips, 2002). Discourse psychologists are particularly interested in group dynamics and group conflicts to map common identities as well as identities that differ from the norm. Group identities are defined by social categories, that is, something you do, think, or say, for example, a certain way to do “skaters,” “pupilness,” or “cleverness” (Staunæs, 2004). Those who differ from the norm make social categories “wrong” and are at risk of being perceived as boundary figures (Staunæs, 2004). By analyzing boundary figures, it is possible to map current normativities (how to do things right), and to map the exotic and skewed (how to do things wrong). *Micro sociology*, in terms of the sociology of deviance and stigma, looks at the deviant’s social identity (Goffman, 1963). Deviation sociology is about social interaction between those whom Goffman refers to as “normal” people and those who have a different trait physically, mentally, or socially. Physical illness is regarded as a stigma, which excludes people from a community of normal people. Goffman analyzes how people define each other by social categories based on expectations of either normal or deviant traits. Social categories are characterized as actual social identities. Goffman’s thinking can provide a greater understanding of the way the adolescents position themselves with different identities.

We analyzed focus group data by looking at both general and specific structures across data. Halkier (2008) proposes discourse analytical techniques to highlight both consensus and disagreements among focus group participants to map current normativities as well as the exotic and skewed. Signe Hanghøj analyzed the transcribed focus group interviews from one theory at a time. In the margin of the transcripts, she highlighted repertoires of linguistic concepts, words, and metaphors and how the analytical concepts within each theory contributed to an understanding of identity (Table 1).

Second, Signe Hanghøj and Bibi Hølge-Hazelton met and discussed all identity types and sorted them into the following main categories: normality, marginality, home and out. Finally, Signe Hanghøj, Bibi Hølge-Hazelton, Kjeld Schmiegelow, and Kirsten Boisen met and reached an agreement on the final categorization of identities.

To ensure rigor of the study we made a thorough transcription of data, and we read the transcripts a number of times to capture all identities, which developed in repertoires of linguistic concepts, words, and metaphors. The research designs were validated by (a) an interview guide to ensure that the participants were asked a similar range of questions, (b) a discussion of analytical concepts and identified identities with all authors, and (c) asking the participants during the interview whether their answers were correctly understood to confirm a true comprehension of their experiences.

## Data Analysis of Photos

Analysis of photographs was done according to the semiotic theory of Roland Barthes (1977) who operates with the image expression called “denotation” (descriptions of the image and metaphors related to these descriptions) and image content called “connotation” (interpretation of the image). Text and images are parts of a complementary relationship because the image is decisive for what is told about it. We analyzed denotations as well as connotations to each photo using Barthes’ theory in combination with the discourse analysis approach. For example, we described the photo related to the identity “Lonely alone” with the following denotation: A “a sofa intended for people’s talk and social life,” and, in contrast, B “the absence of people in the room.” The relationship between A and B were interpreted as a metaphor for loneliness (lack of human interaction). The participant’s associations to the photo (connotations) also pointed to a loneliness discourse “home I am lonely and introvert” and a way of positioning oneself. In the results, one photo will present each type of identity, which is representative of the group of adolescents who identified with it.

## Results

The 14 participants submitted a total of 168 photos to the study and all participants contributed actively in the focus group interviews. In this article, a limited number of photos were chosen to underpin the different types of identities found in the discourse-inspired analysis. To maintain the participant’s anonymity, they are all given fictitious names and faces and identifiable characteristics are blurred.

The results of the analysis suggest normality and marginality as overall identity types. The identities associate with either an out arena or a home arena allowing six general identities to emerge. The identity types are presented with all the subidentities in brackets:

1. Normal identities out (freedom searchers, see me as I am, pain “defier”).
2. Normal identities at home (creative and bookworm).
3. Normal identities home and out (health articulator).
4. Marginal identities out (adherent, illness articulator, lonely among others, reluctantly visible).
5. Marginal identities at home (lonely alone, pain “practicer”).
6. Marginal identities at home and out (dependent, old and weak, wise on life).

## Normal Identities Out

### Freedom Searchers

The 14 participants agreed that youth was linked to freedom, which was different from life as a child (see Figure 1). Youth was explained with the following positive signifiers, which

**Table 1.** Use of theories

<b>Theory</b>	<b>Analytical concepts</b>	<b>Examples from data</b>	<b>Contribution to identity</b>
<b>Critical discourse analysis</b>	Signifiers and Chains of equivalence	Freedom, no obligations, travel, friends, girl-/boyfriends, parties, physically exercising, to be on the move, planning without parents	Freedom searchers
	Interaction control	Oliver leads the conversation; he denies that methotrexate is a valid excuse for not drinking, especially when Freya not even feels sick of it, and also “doctors talk.”	Adherent
	Antagonism	Freya who is adherent versus Oliver who is non-adherent = Adherent and non-adherent discourses are struggling	Adherent
	Hegemonism	Non-adherent discourse, a certain way to behave as young become dominant in the conversation	Adherent
<b>Positioning theory</b>	Interactive positioning	Oliver positions Freya as different and boring, and as one who sticks out from the normal youth community	Adherent
	Reflexive positioning	Emma positions herself as healthy, strong, and fast	Health articulator & Dependent
	Contradictions	However, Emma is also dependent of medicine/ill, and can't do the same as peers	
<b>Discourse psychology</b>	Body signs	Emilie and Liva position themselves as old and weak	Old and weak
	Categories	Oldness and weakness associate to a way to “do” youth.	
	Boundary figures	Peers dissociate from Karen, when she position herself with contrasting categories (ill, old, too young) in public	Illness articulator
<b>Micro sociology (sociology of deviance)</b>	Information control Mixed contacts Passing	Clara and Freya do not talk to their healthy friends about arthritis, and arthritis (stigma) remains hidden	See me as I am
	Potentially discredited Improving position	Clara and Freya perform physical activities to be like healthy peers, even though it is very painful	Pain defiers
	Discredited	Karen talks about her disease to her peers	Illness articulator

Note. This table shows examples of the use of theories and analytical concepts, and how they contributed to analysis of identities in the text.

clearly pointed to a freedom discourse: freedom, no obligations, travel, friends and girl-/boyfriends, parties, physically exercising, to be on the move, and planning without parents:

The special thing about being young is that you spend so much time with your friends, I think . . . and parties and the things you do when you are young, also to have so much freedom to do a lot of different things that I think is really quite special about being young. (Ida)

It is simply this freedom of being young, you're not too young to drive, and you're not too old to . . . all kinds of things you need to . . . it is a good age right here and now. (Julie)

When the adolescents were out and away from home, most of them lived an ordinary youth life with their friends.

### See Me As I Am

Most of the participants had told their closest friends about the disease but had not made their other peers aware of it. Because arthritis often passed unnoted (an invisible stigma), close friends often forgot about it. The participants expressed that arthritis was not a comfortable and fun topic to raise among friends (Figure 2):



**Figure 1.** Discourse: Freedom to go where I want.



**Figure 3.** Discourse: I defy the pain when I ride.



**Figure 2.** Discourse: I do not talk to my friends about arthritis.

It's not something we just talk about over the phone, then it is about what you have experienced. (Clara)

I often find it difficult to talk about such things, a lot about emotions and where it hurts and things like that; those are strange topics for me. (Freya)

Thus, stigma remained hidden when nobody spoke about it:

Actually, I choose to tell it quite late, and then they [friends] become somewhat surprised and say "Why did not you tell me that before?" And I explain it to them "Well, I'd rather have that you see me for who I am and not for the one with arthritis," because I do not want to be that kind of person. (Emma)

I do not want to play the pity card . . . there are not many who know about it because . . . I do not want to be treated as a weaker person. (Oliver)

Petra provided a very exact picture of how she once imagined other adolescents with arthritis looked like:

I had an idea that everyone else was such freaks . . . in wheelchair and things like that. (Petra)

These adolescents kept their stigma secret to anyone but their closest friends, and so they primarily positioned themselves as healthy. They found it hard identifying with arthritis, which they connected to negative signifiers as boring subject, weakness, compassion, freak, and wheelchair. They found it inappropriate to talk about the disease, and thus "they passed," by which they achieved the same respect and recognition as their peers.

### *Pain "Defiers"*

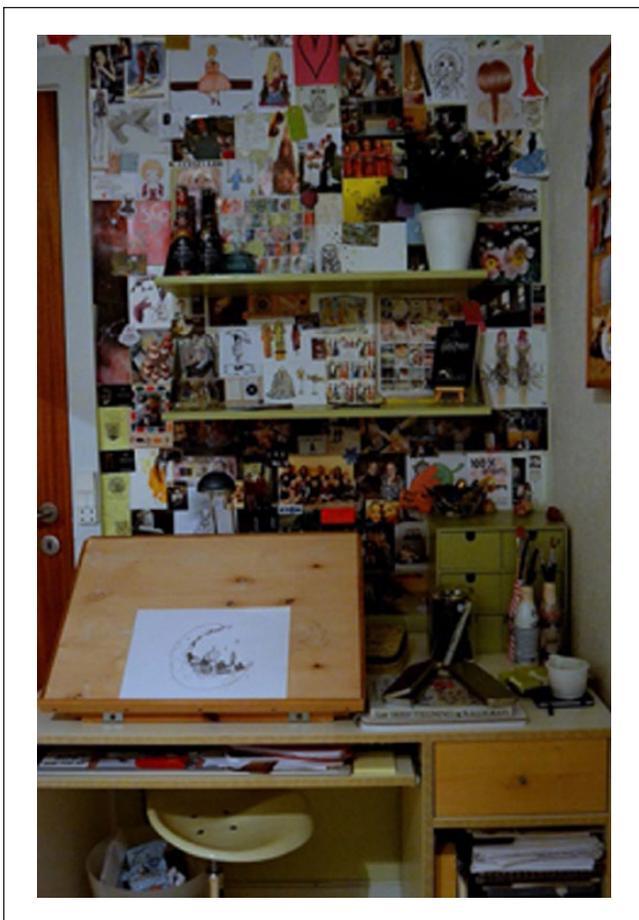
Some of the participants tried to maintain a healthy body by positioning themselves as strong and enduring, though the pain after physical activity was almost unbearable:

It does not restrict me to what I do, so I still exercise, if that's what I want . . .

I do it even though it might hurt . . . but then I just continue. It's like when I ride on my horse, it hurts terribly, but I continue for several hours . . . I just don't think that my disease should stop me at all, so I do everything just to disprove it. (Clara)

Then I say "yes yes I can easily do that," pain comes tomorrow, right? So I push my pain aside all the time, and then suddenly it just comes in a big bag. (Freya)

By positioning themselves as strong and forcing their body to master physical activities, which are commonly considered to be precluded for persons who are hardly affected by illness, they made an effort to "improve their position." The activities were performed even though they were painful (Figure 3). Several adolescents told that they ignored the pain to behave like their healthy peers. Thus, some of the adolescents "did"



**Figure 4.** Discourse: I draw and paint.

normal youth by exercising as other healthy adolescents, and subsequently they took the consequences of their physical efforts by “doing” illness and fatigue at home.

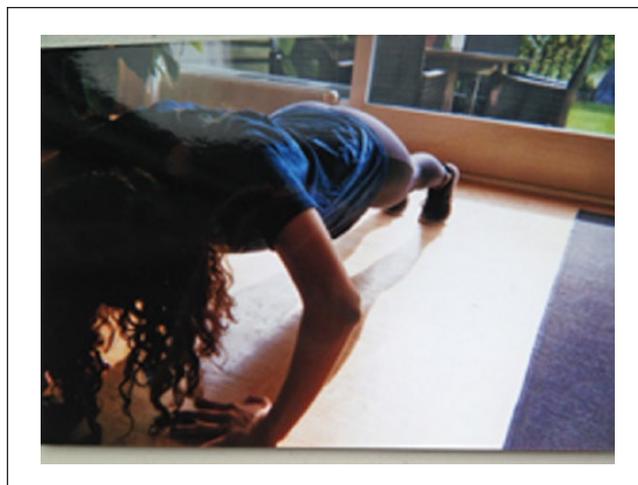
## Normal Identities Home

### *Creative and Bookworm*

Instead of positioning themselves as strong and tough, some of the participants chose a reframing strategy, which implied that they embarked with other less physically demanding areas such as reading, baking, studying, playing music, or being similarly creative (Figure 4). They could not express their identities bodily as adolescents without pain:

I do not feel so physically strong . . . when the others go out and work out, I cannot really be with them, then I prefer to be creative, it's something I can be strong in, it does not require so much of my body, it is not inhibited by disease. (Julie)

Thus, I feel the same way, if there is something I just can't, if I feel a little pain and cannot really go to school then I make a dream-catcher or something . . . I feel that there is so much I can't do physically so I am very happy to be creative. (Ida)



**Figure 5.** Discourse: My body is strong.

Hence, the participants used creativity and sedentary leisure activities to position themselves with something they were good at, and they developed skills that gave them new identities and hope for the future.

## Normal Identities Home and Out

### *Health Articulator*

A recurring feature of the 14 participants' stories was that pain was a determinant for whether the arthritis became a part of their life story. Those who did not feel pain did not feel that the illness changed their lives (Figure 5). Emma explained that arthritis “just (is) an extra stuff in my backpack.” She was one of the few who did not feel physical limitations of her disease neither out nor home because the medicine removed her pain, and because she did not feel any the side effects of the medicine. Physically, she could do the same things as her friends—she exercised, took part in sports in school, got dressed in the morning without help, and she could party and dance. Emma positioned herself as healthy:

My body is really strong, I exercise quite a lot . . . I feel healthy all the time . . . It is only when I have the flu or something, that I feel ill. (Emma)

Emma's body behaved “normally,” and in the description of her body, she used positive signifiers as strong, smooth, and fast.

## Marginal Identities Out

### *Adherent*

Doctors taught the adolescents that alcohol increases the stress on the liver during treatment with Methotrexate. Some were neglecting the doctor's recommendations to live a normal life with friends, where others interpreted the recommendations



**Figure 6.** Discourse: The physician's recommendations can be graduated.

according to their own beliefs. Only one focus group participant, Freya, chose to follow the doctor's recommendations (Figure 6). The other focus group participants (Petra and Oliver) tried to position her as different and boring, and as one who deviated from the normal youth community. Thereby, they highlighted Freya's adherent identity as imbalanced and their own non-adherent identity as normal:

F: . . . it is actually only my girlfriends . . . who completely understand that I cannot drink alcohol

P: Why can't you drink?

F: That's because I take methotrexate

P: Well, I get that too, but I drink, ha ha

F: I drink occasionally, but no more than two drinks, and then I wait for a long time before I can drink again

P: Well okay, do you get sick then?

F: No my liver cannot tolerate it

P: No okay, ha

O: Doctors talk so much

Petra and Oliver denied that methotrexate was a valid excuse for not drinking, especially when Freya did not even get sick, and also "doctors' talk." Oliver did not believe in expert knowledge; he rather stuck to his own experience:

O: I see it like this; if you take a unit alcohol and then take half a liter of water, then the water dissolves the alcohol and so you are able to drink a little more alcohol, right?



**Figure 7.** Discourse: I'm ill all the time.

Then Freya tried to defend herself, but this time a little more uncertain ("I think"). At first she argued that her family would scold her, and next she argued that it was more fun to watch the other being drunk:

F: I just do it like this, otherwise I think, I will receive scolding from everyone in my family . . . I keep away from it because it's more fun to watch the others being drunk.

Oliver possessed the "interaction control" throughout the conversation and set the agenda for the right way to "do" youth.

### *Illness Articulator*

Karen had difficulties in school and with her classmates. "I'm ill all the time," she said, which indicated that she, unlike the other participants, positioned herself as ill among peers, and she did not keep her illness in the home arena (Figure 7). She was regarded as a "boundary figure," because she related to contrasting categories in public—young, ill, and old (adult)—and so she did not fit into the youth community. She said that she did not quite fit in with her classmates when she tried to be like them, and they always took distance from her:

Sometimes I experience that people take a step away from me; it's quite depressing, because I'm just trying to be open and tell how it is, and that it is how I feel, and so I have felt my whole life. Then people get like "Wow that is strange, I don't want to be together with her." (Karen)

Karen considered herself as a very thoughtful and precocious girl who took life seriously because of her arthritis. To counteract this seriousness, she sometimes tried to meet peers with childishness, which, she believed, matched other



**Figure 8.** Discourse: I feel isolated.

13-year-olds' way of being. The classmates found this attempt to be childish and so inappropriate that they dissociated from her:

There are always complaints about what I do, "oh no, it's completely brain dead, what you do" and then it seems like I'm very childish, but it's just because I want to be like the others, and I don't want to seem like this precocious realistic adult who just don't have any fun in life. (Karen)

In Karen's meeting with healthy classmates, "mixed contacts" occurred. In her classmates' eyes, she appeared as "discredited" because she talked about her disease (her differentness) and she appeared as abnormal in her classmates' eyes.

### *Lonely Among Others*

Even among friends, some of the adolescents felt lonely. They felt that even their close relations could not understand them, and they felt isolated from their loved ones, even if they were together (Figure 8):

It's like I'm inside a bubble and you can do the same things as the others, but it's like being in a small hamster wheel . . . you can be with friends, but they can never get close to you because they can never understand you 100% . . . and not even my family, they are always there, and you can hug them and everything, but you are still isolated from them, because they have not even tried it . . . that's how I sometimes feel . . . (Karen)

Ida thought that it was difficult that those people helping her professionally with her treatment did not know how it was to live with arthritis:

The people I speak most with about my disease, they are professionals, it is doctors and it is nurses, thus it's interesting



**Figure 9.** Discourse: I have the feeling of a shining arrow pointing at me.

for them to see how they can help me, but they have not been there, they do not understand how it is. (Ida)

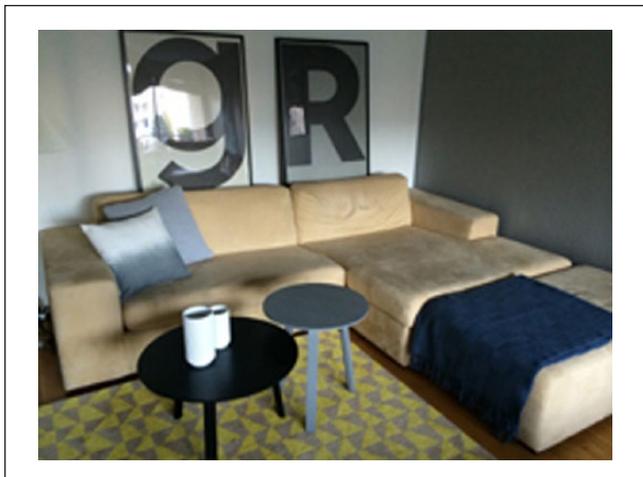
### *Reluctantly Visible*

A reluctant visibility was present when the adolescents were confronted with bodily activities they could not perform. The adolescents were particularly attentive to their ill body when it "met" healthy bodies in sport lessons in school (see Figure 9). "Ill body" also met "healthy body" when the adolescents had to leave class to go to the doctor. Julie and Ida explained,

I feel it like I get unnecessary attention, when I cannot participate in sports in school, then I get a lot of attention from the others because they think "oh no you are so lazy" or something . . . I just feel like I have a great shining arrow above my head, saying "she has arthritis," that is how I feel. (Julie)

I might imagine what people think about me "that it is just because she does not bother," but I really like to, I really like to, but I cannot . . . (Ida)

Being reluctantly visible could be compared with the experience of having a "noising arthritis," which these girls were afraid could disturb the surroundings with its signs of weakness. The adolescents rarely carried visible body signs disturbing normativity (e.g., crutches). Thus, it was mostly the feeling of being visible that affected the adolescents, when they felt physically limited.



**Figure 10.** Discourse: At home, I am lonely and introvert.

## Marginal Identities Home

### *Lonely Alone*

Whereas loneliness among others was manifested as a feeling of not being understood, the loneliness at home was experienced as a physical isolation with speculations about self-esteem and future as well as more existential thoughts about life with a serious illness. Petra and Freya positioned themselves as introvert and lonely in their own company and they explained that there were situations when they actually needed this loneliness when they were at home (Figure 10):

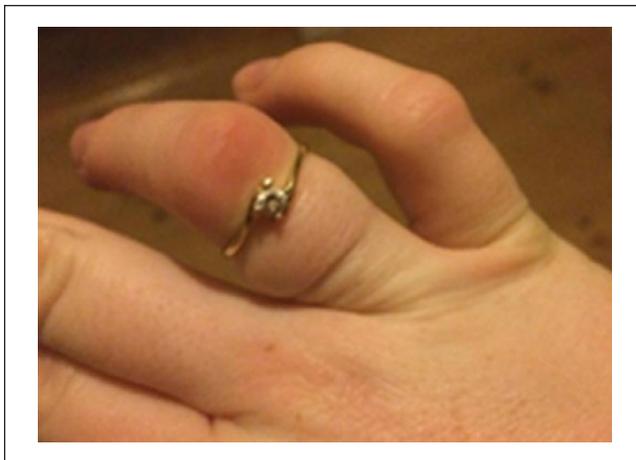
[Sometimes] I feel like being all alone and not talk to any people at all. That's my way of handling it [arthritis], but I also sometimes think it's kind of an unhealthy way, because . . . I worry like crazy, and that is something I'm very often told, I always think plan a, b, c, d with everything and I have always an idea that things are not going to work, and that there is something that will go wrong . . . because I am just filled up with concerns. (Petra)

The winter is nice for me, because then I can shut myself inside and watch TV shows. (Freya)

Furthermore, both girls told that they needed peace to retreat from demands that were being required of them from the surroundings. When they were alone, they only had to deal with themselves and their illness.

### *Pain "Practicer"*

Many of the participants positioned themselves as ill when being with parents and siblings because they lived out the disease at home (Figure 11). They did not want to flag their illness to their peers in school and they spent all their energy to ignore the pain during the day. When they came home, they were drained of energy and often they needed to rest. Another reason to live out pain at home was medicine intake. Some of them needed their parents' help, for example, to administer the



**Figure 11.** Discourse: When I feel much pain I stay at home.

injections. Most of the adolescents experienced fatigue and nausea after medicine intake, which often confined them to bed.

Almost every day when I come home from school, then I am exhausted, I can just lie down and be in pain. (Liva)

Emilie described that she sometimes felt uncomfortable coming home with friends after school because she was so exhausted that she needed to give in for tiredness. She did not want to burden her friends:

My body . . . I sense that it is tired, very tired when I get home from school and in general, just when I have done something, I sense that it is tired, and that I think is not particularly nice because when I'm at home with friends, I do not have much strength, and I sense that my body is very tired. (Emilie)

Petra underpinned that pain and fatigue were not something you wanted to flaunt publicly. The days when she had so much pain that she had to use crutches she stayed at home:

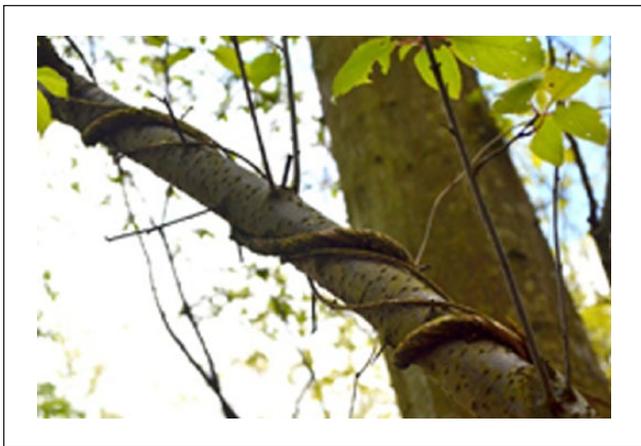
I do not feel like running around with crutches, because I think that's a little . . . so the days when I need to run around with crutches, then I just don't run around and only stay at home and relax a little. (Petra)

Severe tiredness was a sign that the body could not keep up with peers' healthy bodies. Crutches were a clear and very conspicuous disease accessory, which likely would stigmatize the adolescents as ill. In other words, they did not "do" normal youth with fatigue and crutches.

## Marginal Identities Out and Home

### *Dependent*

Dependency on drugs and treatment plans was seen as a major limitation for most participants (Figure 12). Emma, who



**Figure 12.** Discourse: The disease strangles me if I don't take my medicine.

primarily positioned herself as healthy and as “normal” young, also told that she did not have quite the same freedom as her friends and that she could not always do whatever she liked:

I would like to travel after high school, and maybe I want to be a back packer or something along those lines, but I really don't have the option because of the medicine, I get biological medicine every 3 weeks, so I can only travel for 2 weeks maybe, ha ha, so it is perhaps not as fun, ha ha . . . otherwise I have to bring a cooler bag, and that is not really smart when you are a back packer. (Emma)

The description of the identity Freedom searchers showed that the participants described youth with a number of positive signifiers, which pointed to a freedom discourse. However, the participants also described youth with a number of negative signifiers, which points to a limitation discourse: many choices, hard to grasp the future, consequences of choices, school pressures, tied to medicine, tied to the family, linked to the disease, and limitations because of the disease. Sometimes, the disease restricted living a normal life as healthy friends did. Furthermore, some of the participants experienced to be dependent on family and friends to cope with everyday things like getting dressed, tow heavy things, open jars and cans, and take long walks and stairs, and to take care of medicine administration and hospital visits at certain days and times. Because of problems taking care of herself, Ida had to move back to her parents, even though she had left home:

Then I moved back home to mom and dad and then I could get the laundry done . . . the first three weeks I laid on the sofa because I had SO much pain in knees and ankles, . . . I had so much pain that I needed my mother to help me down the stairs in the morning, well it's completely crazy. (Ida)

### Old and Weak

Some of the participants associated their bodies to aging by using terms like *oldness* and *weakness*. Aging was a diametrically opposed category to their biological age. “Oldness”



**Figure 13.** Discourse: My body feels old.

and “weakness” became a way to “do” youth, and a way to position oneself:

Sometimes I feel old, because many old people cannot run as fast as young people of course, and neither can I. (Emilie)

I cannot walk like the others or cycle, and it hurts just walking around in school, and there are many who do not really understand how it can hurt just to walk. Thus, I might feel quite old. (Liva)

The adolescents, who positioned themselves through “oldness” and “weakness,” were those who experienced greatest pain associated with their disease for which reason negative body identifications obviously related to the experience of pain (Figure 13).

### Wise on Life

The adolescents did not only describe the arthritis as something with a negative impact. They described the illness with the following positive signifiers: Something you become wiser of, sharpens the focus in terms of future plans, increased insight into general life crises in others, and I become a better person (Figure 14). On the negative side, some of the participants also described arthritis as something one gets dumb by. The signifiers point to a life experience discourse, as the adolescents felt that they were getting wiser, more focused, and achieved greater understanding of other people on the positive side, and on the negative side,



**Figure 14.** Discourse: I have planned my future.

they also got less perceptive because they lost a normal youth. Freya and Petra explained,

F: Sometimes, I just feel that I have learned so much from it, which I think most adolescents haven't, then I feel a little wiser, ha . . . and also more dumb on some other points

P: Yes, that is where you can feel a little excluded in other contexts . . .

F: Yes exactly . . .

P: One needs to deal with life in a completely different way at a very young age when adolescents in general can just be a little more "day by day." Personally, I have to think about everything I do in relation to my future, and what shall I do, and what can I do and what can't I do, and that is why I think that I have learned a lot about life, what to appreciate, and what is less important.

Thus, the arthritis contributed to some of the adolescent's positioning as serious, wiser on life, and more mature than their healthy peers.

## Discussion

Photo elicitation worked well as an exploratory method because all participants contributed with photos prior to the focus group interviews. The photographs contributed to gain deeper insight into chronically ill adolescents' identity constructions, which may open up for new perspectives. This study adds knowledge about how identities are coupled specifically with home and out arenas, and how adolescence, health, and illness should be "done" in certain ways in these arenas in order for the adolescent not to be excluded from society. Pain seemed to play a central role. When having pain, participants primarily positioned themselves through marginality identities, whereas the absence of pain was associated with normality. Though, it was not the disease itself,

but the experience of pain, that lead to certain ways of identity constructions.

Most of the 14 participants in the study balanced between illness and youth by "doing" illness at home and youth out. It turned out that it could be difficult to be accepted in the youth community if you stepped out of line and "did" illness among peers, for example, by articulating illness or refrain from drinking alcohol with friends. There were certain unwritten rules for how to behave in public to avoid attention. The balance between youth and illness turned out to be an almost constant act. For example, fatigue and pain should be lived out at home, and it could be both embarrassing and uncomfortable if these signs of illness appeared among friends. Similarly, intrusive thoughts about the illness and the feeling of loneliness were predominantly directed inwardly and taken home by the adolescents.

The discourse-inspired analysis led to new perspectives on the concepts of transition because the analysis illuminated the transition periods, partly as categories that created meaning based on the way they were "done" and partly as nodal points to which certain discourses were related. The signifiers related to youth were normality, nightlife, party, alcohol, body worship, friends, outgoing, fun, and freedom. The signifiers associated with illness were abnormality, homelife, oldness, fatigue, pain, parents, being introvert and thoughtful, being boring, dependence, and medication. As discourses create identities, it became urgent for most of the adolescents to position themselves within the discourses where they wanted to belong, for example, as strong and healthy, and to create distance from others' positioning, for example, as being boring. Thus, the adolescents experience two transitions that are associated with incompatible discourses, which is why youth and illness are difficult to reconcile. The results of this study point to the fact that these multiple transitions make chronically ill adolescents not only double-loaded but also torn between identities that are not compatible. Therefore, it can be extremely difficult living with a chronic illness during adolescence.

Some of the findings of this study are in line with the results of a study on adolescents with advanced CKD (Tong et al., 2013). They found that some adolescents felt frustrated about their inability to participate in physical activities to the same extent as others. As in our study, one adolescent with CKD ignored her illness to strive for normality, and some of the adolescents felt that the illness accelerated their maturity and gave them a new perspective on life. In other studies, adolescents also felt embarrassed to tell their peers about their illness (Auslander, Sterzing, Zayas, & White, 2010; Mulvaney et al., 2011); they were worried to feel different from peers (Bullington et al., 2007; Taylor, Franck, Dhawan, & Gibson, 2010), and some feared that peers would learn about their disease (Dziuban, Saab-Abazeed, Chaudhry, Streetman, & Nasr, 2010; Mulvaney et al., 2008). Concerns about feeling different from peers were strongly connected to the feeling of not being normal, which is also a major cause

of non-adherence (Kyngäs, 2000; Simons, McCormick, Mee, & Blount, 2009). This study brings the normality perspective into a new light as it showed how adolescents are in danger of being stigmatized if they stick out from the crowd when “doing” illness outside home. Other studies found that conflicts between adolescents and their parents were a major reason for non-adherence (Hommel & Baldassano, 2010; Naimi et al., 2009). Conflicts with parents were not an issue in the present study; however, parents were mentioned as part of the home arena as they helped administering medication. The home often related to negative discourses on limitation and dependence. At home, the adolescents were sad, introvert, and lived out their disease and pain. This study may indicate that parents can have a difficult task coping with their child’s illness because the adolescent lives out vulnerabilities at home.

### Limitations

Some limitations of the study should be taken into consideration. Even though a purposive sample technique ensured that the participants contained the same characteristics (adolescents with JIA), there might be differences in how a 12-year-old and a 19-year-old adolescent position themselves and think about their illness. Karen, who we identified as a boundary figure because she was “doing” illness in school, which was not accepted by her classmates, was one of the youngest participants in the study. We cannot predict whether an older adolescent would position herself as ill in public. However, we found many similar constructions of identity across age. Another limitation of the study could be the gender distribution. Our sample consisted of 11 girls and three boys. This composition of gender reflected the skewed sex ratio in JIA, as well as an unequal number of boys and girls in the main study (83% girls, 17% boys). However, we did not discover any specific differences in identity constructions between girls and boys in the study except from those who “did” adolescence “wrong” were both girls. Perhaps, a larger sample size could have identified more examples of “imbalanced” identities. The limited sample size also limits the generalizability of the study. Thus, the identities found in this study may not reflect identities of all adolescents with JIA. Furthermore, some of the adolescents in this study had a chronic illness with no identifiable endpoint, a severe degree of pain, recurrent exacerbations, and side effects, and they were all treated with disease-modifying medications. This is why their identity constructions may not be transferred to adolescents with other chronic diseases or to adolescents with milder degrees of JIA. It is likely that identities are constructed in relation to illness rather than youth in adolescents who currently experience, or have previously experienced, severe pain and tiredness, because they are sometimes unable to leave their homes and spend time with their friends. Thus, identity constructions in adolescents with fewer physical complications may be different. Finally, the discourse

theoretical analysis approach led to some specific identities, whereas in another analysis strategic optic, the identities may have been different.

### Clinical Implications

Our study may have clinical implications. It may be suitable to discuss how, when, and to whom adolescents should disclose and discuss their illness because detailed descriptions in public may lead to social isolation and stigma. Ideally, it would be optimal for adolescents to get treatment appointments outside school hours, so they do not need to flaunt their disease because they have to leave class. Parents of chronically ill adolescents can be advised that their child live out vulnerabilities at home, and this can be very difficult to deal with. Finally, it is important for health professionals to know that it can be rather challenging for adolescents to adhere to medical treatment as the medication is kept at home to avoid stigma on the out arena, whereas life on the other side must be lived out and away from home to fit into a normal youth life.

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